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Follow-up to the World Summit for Social Development: Review of relevant United Nations plans and programmes of action pertaining to the situation of social groups

Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Note by the Secretary-General

1. At its forty-eighth session, the General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, contained in the annex to its resolution 48/96 of 20 December 1993.[1] The 22 Rules provide a framework to further the goals of "equality" and "full participation" of disabled persons in social life and development, set forth in the World Programme of Action concerning Disabled Persons.[2]

2. In section IV, paragraph 2, of the Standard Rules, it is stipulated that the Rules shall be monitored within the framework of the sessions of the Commission for Social Development. The appointment of a Special Rapporteur to monitor their implementation within the framework of the Commission for Social Development was also envisaged in that paragraph.

3. In March 1994, the Secretary-General appointed Bengt Lindqvist (Sweden) as Special Rapporteur on Disability of the Commission for Social Development. The Special Rapporteur prepared a report for the consideration of the Commission for Social Development at its thirty-fourth session.[3] On the basis of that report and the findings of the Commission's working group, the Commission adopted resolution 34/2 entitled "Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities".[4] In that resolution, the Commission took note with appreciation of the report of the Special Rapporteur and of his recommendations and welcomed his general approach to monitoring, including the emphasis to be placed on advice and support to States in the implementation of the Rules.

* E/CN.5/2000/1.

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4. At its thirty-fifth session in 1997, the Commission for Social Development considered the report of the Special Rapporteur on monitoring the implementation of the Standard Rules for the period from 1994 to 1996.[5] The Commission took note with appreciation of the valuable work done by the Special Rapporteur, decided to renew his mandate for a further three years and requested the Special Rapporteur to prepare a report for submission to the Commission at its thirty-eighth session in 2000.[6]

5. In section IV, paragraph 12, of the Rules, it is further stipulated that at its session following the end of the Special Rapporteur's mandate, the Commission should examine the possibility of either renewing that mandate, appointing a new Special Rapporteur or considering another monitoring mechanism, and should make appropriate recommendations to the Economic and Social Council. The present mandate of the Special Rapporteur will come to an end in 2000. The Commission is requested to make its recommendations in that regard to the Economic and Social Council and the General Assembly.

6. It might be recalled that the activities of the Special Rapporteur and his panel of experts are funded by voluntary contributions.[7] During his two 3-year mandates, from 1994 to 1997 and from 1998 to 2000, respectively, 10 Governments and the National Council on Disability of the United States of America[8] contributed some US$ 750,000 to a special trust fund account established by the Secretary-General to finance the activities of the Special Rapporteur. The Government of Sweden provided financial and in kind support to maintain the office of the Special Rapporteur. The Government of Canada made a direct financial contribution. Draft working data on contributions received and expenditures in support of the two mandates are presented in tables 1 and 2, respectively, as at 15 November 1999, and will be updated to 31 July 2000.

Table 1

Contributions through the United Nations earmarked for the activities of the Special Rapporteur from August 1994 to July 2000

(United States dollars)

Country	*Aug. 1994-July 1995*	*Aug. 1995-July 1996*	*Aug. 1996-July 1997*	***Subtotal Aug. 1994-July 1997***	*Aug. 1997-July 1998*	*Aug. 1998-July 1999*	*Aug. 1999-July 2000*	***Subtotal Aug. 1998-July 2000***	***Total Aug. 1994-July 2000***
Austria	9 094		8 110	**17 204**		7 941		**7 941**	**25 145**
China	10 000	10 000	10 000	**30 000**	10 000	10 000	10 000	**30 000**	**60 000**
Denmark	100 000			**100 000**		100 000		**100 000**	**200 000**
Finland	10 000		10 000	**20 000**				**0**	**20 000**
Iceland				**0**		5 000		**5 000**	**5 000**
Japan	10 000	10 000	10 000	**30 000**	9 100	7 500	7 500	**24 100**	**54 100**
Netherlands			83 052	**83 052**		39 695		**39 695**	**122 747**
Norway	49 978		25 000	**74 978**		50 000		**50 000**	**124 978**
Philippines				**0**	3 000			**3 000**	**3 000**
United Kingdom of Great Britain and Northern Ireland		31 146		**31 146**				**0**	**31 146**
National Council on Disability of the United States of America		24 500	25 000	**49 500**	25 000			**25 000**	**74 500**
Other				**0**				**0**	
Redeployment from United Nations Voluntary Fund on Disability sub-allotment account for Working Group on Standard Rules	30 000			**30 000**				**0**	**30 000**
Total	**219 072**	**75 646**	**171 162**	**465 880**	**47 100**	**220 136**	**17 500**	**284 736**	**750 616**

Table 2
Expenditures relating to earmarked activities of the Special Rapporteur from August 1994 to July 2000
(United States dollars)

Description/activity	*Aug. 1994-July 1995*	*Aug. 1995-July 1996*	*Aug. 1996-July 1997*	***Subtotal Aug. 1994-July 1997***	*Aug. 1997-July 1998*	*Aug. 1998-July 1999*	*Aug. 1999-July 2000*	***Subtotal Aug. 1998-July 2000***	***Total Aug. 1994-July 2000***
Honorarium	20 000	20 000	20 000	**60 000**	24 000	24 000	24 000	**72 000**	**132 000**
Panel of experts meetings	38 273	37 260	48 585	**124 118**		54 432		**54 432**	**178 550**
(New York, 15-17 February 1995)									
(New York, 10-14 June 1996)									
(Ferney-Voltaire, France, 20-25 May 1997)									
(Ferney-Voltaire, France, 20-22 October 1998)									
Travel of Special Rapporteur and his assistant	27 056	47 497	61 773	**136 326**	14 377	49 773	15 540	**79 690**	**216 016**
Subtotal									**526 566**
Add 13% support									68 454
Total									**595 020**

7. During the two mandates of the Special Rapporteur, a number of Governments and organizations of persons with disabilities at national, regional and interregional levels have submitted requests for co-financing assistance from the Voluntary Fund on Disability for building national capacities to further implement the Standard Rules. These data for approved and pipeline projects as at 15 November 1999 are summarized in table 3. The selected project experiences are discussed in reports of the Secretary-General on the implementation of the World Programme of Action concerning Disabled Persons (E/CN.5/1999/5 and A/54/388 and Add.1).

Table 3
Capacity-building projects related to the Standard Rules supported by United Nations Voluntary Fund on Disability (1997-1999)

Project No.	*Country/region*	*Short title*	*Implementing agency*	*Total budget (United States $)*	*Grant (United States $)*
	Africa				
MAU/99/D10	Mauritania (Nouakchott)	Séminaire sous-régional magrébin sur les Règles (Nouakchott, December 1999)	Action pour le développement social en Mauritania	**99 600**	40 100
MOZ/97/D33	Regional Southern Africa	Workshop on equalization of opportunities: legislation, gender and the socio-economic situation of landmine victims, women and children with disabilities (Maputo, 10-13 August 1999)	Southern Africa Federation of the Disabled (Zimbabwe)	**87 000**	28 200
RAF/99/D36*	Senegal (Dakar)	Seminar for francophone member States of the African Rehabilitation Institute on "Standard Rules on Equalization of Opportunities for Persons with Disabilities (Dakar, December 1999)	African Rehabilitation Institute (Dakar office)	**35 168**	28 000
ZIM/97/D28	Zimbabwe (Harare)	First African Rehabilitation Institute seminar on the Standard Rules (Harare, 11-13 February 1998)	African Rehabilitation Institute (Zimbabwe office), in cooperation with International Disability Foundation	**22 800**	13 300
	Asia and Pacific				
INT/99/D27*	Hong Kong	Interregional seminar and symposium on international norms and standards relating to disability	Equal Opportunities Commission, Hong Kong, Special Administrative Region of China, in cooperation with Hong Kong University, Faculty of Law, Centre for Comparative and Public Law	**95 000**	70 000
	Latin America and the Caribbean				
MEX/96/D24	Mexico (Guadalajara)	Workshop on promoting accessible urban environments in preparation for 1998 World Assembly of Disabled Peoples' International at Guadalajara (Guadalajara, Mexico, 19-25 August 1997)	Disabled Peoples' International in cooperation with Municipality of Guadalajara, State of Nayarit, and Government of Mexico	**70 000**	30 000
RLA/97/D17	Dominican Republic (Santo Domingo)	Training of trainers in monitoring the implementation of the Standard Rules in Central America and the Caribbean (Santo Domingo, Dominican Republic, 13-18 April 1998)	Disabled Peoples' International in cooperation with the Government of Dominican Republic and the Asociación Dominicana de Rehabilitación, and with the participation of the Federación Nacional Dominicana de Discapacitados	**66 000**	49 000
	Interregional				
INT/98/D30	Berkeley (United States of America)	Consultative Expert Meeting on Law and Disability Policies (Berkeley, United States of America, 8-12 December 1998)	World Institute on Disability in association with University of California at Berkeley	**50 000**	35 000
Total				**525 568**	**293 600**

* Pending financial approval.

8. The final report of the Special Rapporteur on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities during his second mandate is annexed to the present note.

Notes

[1] www.un.org/esa/socdev/dissre00.htm.

[2] A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII (www.un.org/esa/socdev/diswpa00.htm).

[3] A/50/374, annex.

[4] *Official Records of the Economic and Social Council, 1995, Supplement No. 4* (E/1995/24), chap. I, sect. E.

[5] A/52/56, annex (www.un.org/esa/socdev/dismsre0.htm).

[6] *Official Records of the Economic and Social Council, 1997, Supplement No. 6* (E/1997/26), chap. I, sect. A, subsequently adopted as Economic and Social Council resolution 1997/19 of 21 July 1997.

[7] General Assembly resolution 48/96, annex, sect. IV, para. 2.

[8] The Government of Sweden provides in-kind support for the operations of the Office of the Special Rapporteur in Stockholm.

Annex

Final Report of the Special Rapporteur of the Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on his second mission, 1997-2000

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Any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities

Commission on Human Rights
Resolution 1998/31

Preface

In my capacity as Special Rapporteur for monitoring of the implementation of the Standard Rules on Equalization of Opportunities for Persons with Disabilities, I have the honour to deliver my final report on the second period of monitoring (1997-2000) to the Commission on Social Development. It has been a privilege and a stimulating task to act as Special Rapporteur in this area. I want to express my sincere appreciation to the Economic and Social Council for showing confidence in me by renewing my mandate for a second period. I also would like to thank all those Governments that have contributed financially to this project, including the Government of Sweden, which has provided me with office resources throughout the entire exercise.

From the beginning and during the whole period of monitoring, I have enjoyed full support from the Under-Secretary-General of the Department of Economic and Social Affairs, Nitin Desai, and excellent professional advice from Andrzej Krassowski and his group at the Division for Social Policy and Development. I have received good cooperation with a number of United Nations agencies, in particular with the World Health Organization (WHO), which, in close cooperation with me, has conducted a global survey on the implementation of a number of Rules. I also want to express my appreciation for the excellent work performed by Eva Sagström in my Swedish office.

One key element in this monitoring exercise has been the panel of experts, established in 1994 by six major international non-governmental organizations in the disability field. The panel members, five men and five women, representing all regions and with different experiences of disability, have provided valuable guidance. They have also been very understanding when limited resources have made it impossible to pursue all good ideas and initiatives.

Finally I want to thank all those Governments and non-governmental organizations that have provided information for my work.

I. Background and framework for mission

A. Background

1. Variations in physical, mental and sensory functioning have always existed among human beings. Yet, people with functional limitations — disabilities — have always run the risk of being excluded and marginalized. Throughout the centuries we have designed and constructed our societies as if persons with disabilities did not exist, as if all human beings can see, hear, walk about, understand and react quickly and adequately to signals from the world around them. This illusion, this misconception about human nature, this inability to take the needs of all citizens into account in the development of society is the main reason for the isolation and exclusion of persons with disabilities, which we can observe in different forms and to different degrees all over the world. It will take a long time to change this pattern of behaviour, which is deeply rooted in prejudice, fear, shame and lack of understanding of what it really means to live with a disability. However, international efforts to improve the living conditions for persons with disabilities have begun and progress is being made.

2. A more systematic effort to improve living conditions of persons with disabilities started long ago in the emerging industrialized nations. During the last 50 years the so-called advanced welfare states have developed comprehensive programmes and services in order to meet the needs of persons with disabilities. For a long time, however, the common approach of all these programmes was limited to various forms of support to the individual and were organized as disability-specific services outside the mainstream of society.

3. In the 1960s and 1970s the awareness started to grow, especially among disabled people in some countries, that participation in the activities of society could take place only if the environment and general services and activities were also designed to meet the needs of persons with disabilities. A new perspective developed in disability policy, which brought the lack of access in the surrounding society into focus and emphasized the right to participation.

4. When the United Nations proclaimed the International Year of Disabled Persons in 1981, it was an event of

historical importance. The adoption of the theme of "*Full Participation* and *Equality*" for the activities during the Year must be considered a major political breakthrough for a human rights-based perspective in the field of disability.

5. The World Programme of Action Concerning Disabled Persons, which was adopted by the General Assembly by resolution 37/52 of 3 December 1982, formulated this philosophy and identified a number of important areas for action. For the first time in international disability affairs, the World Programme requested all human rights bodies to give attention to disability-related problems. Other major contributions by the World Programme were the presentation of the concept of the equalization of opportunities as a new area for intervention and the recognition of the right of disabled persons and their organizations to participate in decision-making in matters concerning themselves.

6. The International Year and the World Programme of Action signalled a process of change and development, which started during the International Decade of Disabled Persons (1983-1992) and which continues today, nearly 20 years later. During the first years of the Decade a lot of attention was given to disability matters in many countries, however, a few years later, this interest seemed to fade. This was noted at the mid-term evaluation of the Decade, made at an expert meeting in 1987. In the report from the meeting a number of measures were suggested to strengthen the leadership role of the United Nations in implementing the new disability policy. The final response to this request was the elaboration and adoption of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

7. The Standard Rules express the same philosophy about disability as the World Programme of Action. However, there are some important additions made as a result of experience gained during the Decade. The responsibility of Governments of Member States in the implementation process is more clearly outlined in the Rules. The most obvious new element in the Standard Rules, however, is the establishment of an active and separate monitoring mechanism.

B. Terms for monitoring

8. One of the most significant features of the Standard Rules is that their implementation was to be actively monitored, as outlined in chapter IV of the Rules, which contains a fairly detailed description of the monitoring mechanism:

> "The purpose of a monitoring mechanism is to further the effective implementation of the Rules. It will assist each State in assessing its level of implementation of the Rules and in measuring its progress. The monitoring should identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules."

9. There are three actors involved in the monitoring task. The Standard Rules outlined that monitoring should take place within the framework of the sessions of the Commission for Social Development, that a special rapporteur should do the actual monitoring work and report to the Commission and that non-governmental organizations (NGOs) in the disability field should be invited to establish a panel of experts, to be consulted by the Special Rapporteur.

10. In March 1994 the Secretary-General, Boutros Boutros-Ghali, appointed me Special Rapporteur. In September 1994 a panel of 10 experts was established by the following six international organizations: Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf and World Federation of Psychiatric Survivors and Users.

11. The activities during the first monitoring period were reported to the Commission for Social Development at its thirty-fifth session (A/52/56, annex).

12. At its session of 1997, the Economic and Social Council, following the recommendations by the Commission for Social Development, decided to renew the mandate of the Special Rapporteur for a further period of three years, from 1997 to 2000 (Council resolution 1997/19). The activities of the Special Rapporteur were also endorsed by the General Assembly in resolution 52/82 of 12 December 1997.

13. A precondition for the whole monitoring exercise was that extrabudgetary funding could be raised for the majority of the activities. During the first period of monitoring, 11 Governments contributed financially to the project. Altogether six Governments have contributed during this second period. The total amount of these contributions is estimated at $700,000. The special service agreement, between the Secretariat and the Special Rapporteur, signed in August 1994, has been kept during the second period of monitoring (1997-2000). This includes the arrangement that the Special Rapporteur should run his work from a small office in Sweden and that the Secretariat would assist with advice and administrative services.

C. Guidelines by the Commission for Social Development

14. At its thirty-fifth session, the Commission for Social Development decided to recommend the renewal of the mandate of the Special Rapporteur for a further period of three years, so as to make it possible to continue the monitoring of the implementation of the Standard Rules. In its resolution 35/2, the Commission:

Urged the Secretary-General and Governments to further the effective implementation of the Standard Rules and to emphasize the dimension of human rights, including that dimension for persons with developmental and psychiatric disabilities

Invited the Special Rapporteur and the Committee on the Rights of the Child to pursue and enhance their cooperation to ensure that the rights of children with disabilities are fully addressed in the Committee's reporting process

Requested the Special Rapporteur to pay special attention to the situation of children with disabilities when monitoring the implementation of the Standard Rules.

15. These guidelines by the Commission have played an important role in the activities of the Special Rapporteur during the second period of monitoring. An account of the activities in connection with each particular aspect can be found under separate headings of the report.

D. Meetings of the panel of experts

16. During the second monitoring period (1997-2000), three meetings of the panel of experts were planned. The first meeting was held in May 1997. Two major subjects were discussed. The panel analysed the outcome of the first monitoring period and discussed the activities to be carried out during the second period. A number of United Nations agencies participated and informed the panel about their ongoing activities. The panel members were invited to present their views and in this way a consultative process was established.

17. At the second meeting, which was held in October 1998, some new developments were discussed, including the adoption of resolution 1998/31 by the Commission on Human Rights, containing a number of important recommendations calling for follow-up action from the NGO community, and the development of a disability policy by the World Bank.

18. Consultations with a number of United Nations agencies were continued and a preliminary discussion was held concerning the promotion of the United Nations disability policy after the end of the second monitoring period.

19. A third meeting of the panel will take place in connection with the thirty-eighth session of the Commission for Social Development in February 2000.

II. Account of the activities of the Special Rapporteur

20. When my mandate was renewed by the Economic and Social Council on 27 July 1997 (resolution 1997/19), no major change was made in the terms of reference for my work. Therefore, in accordance with the guidelines in chapter IV of the Standard Rules document, I have continued to give advice to Governments upon request, to participate in seminars and conferences to discuss the practical implementation of the Rules and to study the implementation of the Rules worldwide through the use of surveys. It has to be borne in mind, however, that these activities had to be carried out within limited available resources. I would also like to add that it took nearly one year of the second monitoring period before new contributions from Member States started to come in.

A. Promotion of the implementation of the Standard Rules

21. During the second period of monitoring, I visited the following countries in transition: Mongolia, Armenia, Bulgaria, Romania and Russia. With the support of the Council of Europe I have been involved in the planning of a national conference on disability policy for the Russian Government, organizations of persons with disabilities and representatives of all regions of the Russian Federation. Unfortunately, the Conference has been postponed twice.

22. One serious problem for many of the countries in transition is that they have not yet developed guidelines for a modern disability policy. In practically all countries in transition there are very serious problems in handling the issue of large institutions for the disabled. Severely disabled people, mainly persons with intellectual, psychiatric and multiple disabilities, have spent their whole lives in such

institutions. The attention given to this problem is increasing both in the countries concerned and among international development cooperation agencies.

23. Another problem, shared by many countries in transition, has to do with the relations between existing NGOs. Old organizations exist for groups of the blind and the deaf, because they were accepted by the old system as partners in creating employment opportunities. For other groups of disabled persons, new organizations are being formed and there are sometimes difficulties in developing good working relations between these different organizations.

24. Since 1997, I have also visited a number of developing countries to discuss disability policy, among others, Thailand, Jordan, Chile, Uruguay, Mexico and Costa Rica. The programmes I have seen during my visits have varied considerably. In some cases our dialogue has concerned rather basic issues of disability policy. In other cases new laws had been adopted and our discussions dealt with issues of implementation. In some instances I have formulated recommendations in a follow-up letter to the President or the Prime Minister of the country concerned. These letters have often played a role in the development of new measures.

25. During this second period I have also participated at international conferences, some of which have raised new subjects or dealt with the Standard Rules from a specific perspective. In 1997, I participated at a conference organized jointly by the Economic and Social Commission for Asia and the Pacific and Rehabilitation International. I was invited to speak at the "Meeting of senior officials to mark the mid-point of the Asian and Pacific Decade of Disabled Persons (1993-2000)" (Seoul, 26-29 September 1997). In my statement, I pointed to the fact that the Agenda for Action, which forms the basic document for activities during the Decade of Disabled Persons, and the Standard Rules were elaborated simultaneously. They are of the same spirit but serve somewhat different purposes. The Standard Rules are a set of guidelines while the Agenda for Action mainly identifies a number of important areas for development. The two could, and in my opinion, should be combined in national efforts to improve living conditions for persons with disabilities. Everything should be done to avoid duplication of work and the two monitoring mechanisms should exchange information more systematically.

26. In 1998, I participated at a world forum on human rights and blind people, held in Uruguay (Montevideo, 16-18 November 1998). In my statement I pointed to the new and important opportunities for strengthening the rights of persons with disabilities emerging through the developments in the field of human rights in recent years. I emphasized the key role that has to be played by organizations of persons with disabilities in spearheading this development. I also used the opportunity to congratulate representatives of countries on the American continent for the progress they have achieved in drafting a regional convention on the rights of disabled people.

27. In January 1999, an Africa seminar on development cooperation, disability and human rights was organized by Disabled People South Africa and the Swedish Organization of Handicapped-International Aid Foundation (SHIA). The conference adopted a resolution proposing an African decade of disabled people during the years from 2000 to 2009.

28. In my speech I gave an account of the main recent events in the human rights area. I also permitted myself to make the following suggestions concerning the issue of an African decade of disabled people:

(a) The Governments of Africa should recognize, support and actively participate in the programmes of the decade;

(b) The organizations of disabled people must be directly and actively involved at all stages and levels of the programme;

(c) There must be an efficient planning and coordinating function for the programme;

(d) Governments should include disability needs in their general negotiations for development cooperation;

(e) There should be an agreed overall programme for the decade;

(f) Sufficient financial backing for the core activities of the programme must be obtained;

(g) The mobilization of disabled people should form a core activity within the programme.

29. A Pan-Arab symposium on the Standard Rules was co-organized in Amman by the Jordanian Government and the Jordanian Swedish Medical Association from 18 to 20 September 1997. Representatives of Governments, professionals and NGOs from 12 Arab countries participated. A statement was adopted in order to guide the development in the different countries. The following recommendations might be mentioned:

(a) Governments should proclaim their commitment to achieve the goal of full participation and equality for persons with disabilities;

(b) Governments should adopt national procedural work plans for the implementation of the Standard Rules through the ministries concerned and other actors;

(c) Governments should recognize the role of organizations of disabled people in representing their groups in matters concerning them;

(d) A national council should be established in each country;

(e) Governments should recognize community-based rehabilitation to involve the local community in raising the standards of disabled persons.

B. Third global survey in collaboration with the World Health Organization

30. The first four Rules in the Standard Rules document are gathered under the heading "Preconditions for Equal Participation". The message conveyed is that measures in these areas must be taken because they constitute necessary measures to enable the individual to participate actively in the community. Three of these Rules, medical care, rehabilitation and support services (including the provision of devices and equipment) are areas of responsibility for the World Health Organization (WHO).

31. In 1998, in discussions between the panel of experts, representatives of WHO and myself, it was agreed that a survey on the implementation of the Rules in these areas should be conducted. WHO offered to make the survey.

32. Information was gathered in 1999 through a questionnaire, sent to all 191 Governments of States members of WHO and to more than 600 national NGOs in the disability field. The information collected covers issues related to the following four Rules: Rule 2 — medical care, Rule 3 — rehabilitation, Rule 4 — support services and Rule 19 — personnel training. The questionnaire, consisting of 35 questions, was distributed in April 1999.

33. The objective of the study was twofold: to identify government policies regarding medical care, rehabilitation, support services and personnel training and to identify strategies adopted and problems encountered when working in the field of medical care and rehabilitation of persons with disabilities.

34. Respondents were asked to answer the questionnaire in order to identify the official policy of the country. In total, 104 Governments responded, a result which must be deemed very satisfactory.

35. Replies were received from countries representing different regions of the world: 17 from the Americas, 25 from Europe, 20 from the Western Pacific region, 4 from the South-East Asian region, 11 from the Eastern Mediterranean region and 27 from Africa.

36. A classification according to socio-economic criteria of the Governments responding shows that there are 18 developed-market economies, 9 countries with economies in transition and 77 developing countries, of which 24 are least developed countries.

37. Replies were received from 115 NGOs. A classification of NGO responses is as follows: 18 responses were received from member organizations of Disabled Peoples' International; 28 responses from member organizations of Inclusion International; 24 responses from member organizations of Rehabilitation International; 23 responses from member organizations of the World Blind Union; 14 responses from member organizations of the World Federation of the Deaf; and 8 responses from member organizations of the World Federation of Psychiatric Survivors and Users. The total number of countries covered by responses from Governments and NGOs is 130.

38. Government information was provided by the division or unit within the ministry responsible for medical care, rehabilitation and support services to persons with disabilities (usually the ministries of health and/or social affairs). Although the constraints imposed by this method of compiling information — which presupposes that the survey will be answered by the most well informed official within the field and that the official will take the time to find answers elsewhere in the event that he/she does not have the answer — the survey represents a unique distillation of information on policy and practice worldwide. It will hopefully be of assistance to policy makers, administrators, rehabilitation specialists and representatives of organizations in the disability field. The study was carried out in close cooperation with my office and will provide a welcome and significant contribution to our knowledge and understanding of the world situation. The full report on the outcome of the survey will be published by WHO in 2000.

39. The presentation in this report, which was made while the analysis of the outcome of the survey was still under way, consists of a selected number of more general questions on each Rule. They mainly concern to what extent services in the defined areas exist, the involvement of governments and other entities and the influence of persons with disabilities and their organizations in these services. Unfortunately, it was not possible to take replies from national NGOs into account.

Medical care

40. According to the opening sentence of the Rule on medical care, "States should ensure the provision of effective medical care to persons with disabilities". The first question concerned the extent to which States comply with this recommendation. An overwhelming majority of Member States (99 of 104) provide services to persons with disabilities. Medical care for children with disabilities is included within the general medical care system in 90 countries.

41. According to the first paragraph of the Rule on medical care, "States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment".

42. The great majority of countries include prevention and treatment of impairment and rehabilitation techniques in the medical care system and other programmes. Less common are programmes for counselling of parents and early detection and diagnosis. Fifteen countries do not have such programmes.

43. Another question concerned the degree of involvement of organizations of persons with disabilities in the planning and evaluation of these programmes. In the majority of countries (59 of 103), organizations of disabled people are sometimes involved. In only three countries, organizations of persons with disabilities are always involved, whereas in 12 countries organizations of disabled people are never involved in planning and evaluation of medical care programmes. In 29 countries those organizations are often involved.

44. One question requested information as to whether persons with disabilities receive regular medical treatment to preserve or improve their level of functioning and, in countries where they do not, what criteria determines the provision of such care. In 85 of 103 countries, persons with disabilities receive regular medical treatment. In the 18 countries where medical treatment is not provided, the following reasons were indicated: lack of specific programmes (16), lack of staff (12), lack of training (8), negative societal attitudes (9) and economic constraints in the family (12).

45. One question concerned the issue of funding of medical care. Responses indicated that patients in 31 countries pay the full costs themselves. In the remaining countries, medical care is either provided free of charge or covered by mixed systems with patient payment, state subsidies or social insurance. In the 62 countries responding to the question about social insurance coverage of medical care expenditures, the following might be observed: there are 22 countries in which 20 per cent or less of the population are covered by social insurance schemes; and in 27 countries between 81 to 100 per cent of the population are covered by social insurance schemes. The discernible pattern is that when medical care is paid by social insurance, it is either for a small portion of the population (often government-employed individuals) or it is for almost everybody.

46. One question concerned the provision of medical care in villages and poor urban areas. Of the 102 countries which responded, 97 indicated that services are provided in these areas. Of these 97 countries, 88 indicated that they provide primary health care, and 44 indicated that they provide medical care through community-based programmes.

47. Finally, respondents were asked to indicate what services are provided to facilitate information and communication on medical care for persons with disabilities. According to the responses received, the most frequent service provided is easy-reading information (62 of 104 responding countries). Fifty countries provide sign language interpretation and one third of the countries provide information in Braille of information on tape.

Rehabilitation

48. In a first general question, information was requested as to what extent national rehabilitation programmes are provided in Member States. Seventy-three of the 102 countries which responded indicated that national rehabilitation programmes exist.

49. Fifty-one countries (of 104 responding) provide community-based rehabilitation programmes at local levels. Nearly as many provide it at district levels. Thirteen countries indicated that they have no community-based rehabilitation. Concerning institutional rehabilitation, responses indicated the following: 74 countries have rehabilitation institutions at the national level, 56 at the provincial level, 46 at the district level and 22 at the local level. In eight countries no institutional rehabilitation programmes exist.

50. One question concerned which groups receive rehabilitation services. Generally, the responses indicated that rehabilitation programmes are available for many groups in most countries. They are most frequently provided to persons with mobility impairments (99 of 104 responding), hearing impairments (90), visual impairments (89), intellectual disabilities (86) and to the deaf (84). It is worth observing that even for learning problems (e.g. dyslexia),

rehabilitation services are provided in a considerable number of countries (69). There are rehabilitation services in as many as 74 countries for persons with mental illness.

51. These high frequencies are in themselves encouraging, but it must be added that they tell little about the actual availability for all those persons in the different groups who are in need of rehabilitation. The availability may differ from covering all who are in need to a small fraction of the group concerned. It must also be borne in mind that the figures above indicate that no services are available in a considerable number of countries: for instance, for persons with hearing impairments in 14 countries and for those with visual impairments in 15 countries.

52. One question concerned in which ways persons with disabilities, their families and their organizations are involved in rehabilitation services. According to the information received, persons with disabilities are most often involved through community-based rehabilitation and as trained teachers, instructors and counsellors and are least involved in the formulation and evaluation of rehabilitation programmes. The same pattern is to be found concerning the families of persons with disabilities, though families are more frequently involved in the above-mentioned activities than persons with disabilities themselves. Regarding the organizations of persons with disabilities, the reverse pattern emerged. Organizations are most frequently involved in the design and organization of rehabilitation services and in the formulation and evaluation of rehabilitation programmes. Representatives of organizations are also most involved as trained teachers. It must also be noted that in a great number of countries, organizations are not involved at all. This is also the case, and even to a greater extent, for persons with disabilities and their families. Regarding community-based rehabilitation, organizations participate to the same degree as persons with disabilities — in 44 countries they take part in such rehabilitation.

Support services

53. In the present report we have selected only questions concerning the provision devices and equipment (crutches, prostheses, hearing aids, visual aids, etc.) to persons with disabilities.

54. Information was requested about government involvement in the provision of such devices. In 87 of the 96 countries providing information on this issue, Governments are involved in the provision of devices and equipment. This high level of involvement is encouraging, but at the same time it must be observed that this frequency of involvement does not indicate to what extent persons with disabilities in need of devices and equipment really get services.

55. A question concerning the funding for such devices and equipment gave the following result. One hundred and four countries responded. The most common way of funding this service is through shared responsibility between government ministries and persons with disabilities. In 28 countries government ministries or municipalities pay fully for such devices and equipment, in nine countries the costs are paid fully by social insurance schemes, in 18 countries they are paid fully by persons with disabilities themselves and in 13 countries NGOs pay fully for assistive devices and equipment. In 32 countries government ministries or municipalities do not pay at all for the provision of these devices and equipment.

56. Concerning what kinds of devices and equipment are provided by Governments, the outcome is the following: the most frequently provided aids are crutches (87 of 104 responding); in 83 countries prostheses/orthoses are provided; in 77 countries wheelchairs are provided; in 64 countries hearing devices are provided; in 62 countries visual aids are provided; in 48 countries devices for daily living are provided; and in 23 countries computers are provided. Devices for people with mobility impairments are most frequently provided, followed by equipment for persons with hearing or sight impairments. Naturally, there is a cost element involved in the different levels of provision of various kinds of equipment. One surprising result is that devices for daily living are not provided by more than half the number of countries providing information.

57. Information was also requested concerning the provision of interpretation services for hearing impaired people: 67 of the 100 countries providing information responded that interpretation services are provided.

58. Information was requested concerning the degree of involvement by persons with disabilities and/or their organizations in the planning of support services. In almost one third of the countries responding to the question, persons with disabilities and/or their organizations are not involved in this process. In 68 of the 99 countries providing information, persons with disabilities are involved in the planning of support services.

Personnel training

59. The first question concerning personnel training was whether Governments ensure that all authorities/agencies providing services in the disability field give training to their personnel. Of 96 responding Governments, 64 indicated that training is not ensured.

60. Between 76 and 47 Governments indicated that disability is a component in the professional training of different groups of staff (physiotherapists, nurses, social workers etc.) in the areas of medical care and rehabilitation.

61. Forty-three Governments (of 92 responding) indicated that they consult with organizations of persons with disabilities when developing staff training programmes.

62. The most remarkable result from this part of the study is that one third of the Governments that participated in the study do not ensure that authorities/agencies providing services in the disability field offer training to their personnel.

C. Progress in human rights

63. One of the most important areas of development during recent years concerns the human rights of persons with disabilities. As Special Rapporteur on Disability of the Commission for Social Development, I have been invited by the Commission on Human Rights to participate in this process. Before giving an account of the recent events, I should like to describe the process, which had already started in connection with the International Year of Disabled Persons.

64. The World Programme of Action concerning Disabled Persons (A/37/351/Add.1 and Add.1/Corr.1, sect. VIII) includes a section on human rights and disability. The following recommendations are of particular interest:

> "Organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on disabled people should ensure that such instruments fully take into account the situation of persons who are disabled. (para. 164)
>
> "Particular conditions may exist which inhibit the ability of disabled persons to exercise the human rights and freedoms recognized as universal to all mankind. Consideration should be given, by the United Nations Commission on Human Rights, to such conditions. (para. 166)
>
> "Incidents of gross violation of basic human rights, including torture, can be a cause of mental and physical disability. The Commission on Human Rights should give consideration, *inter alia*, to such violations for the purpose of taking appropriate ameliorative action." (para. 168)

65. On 29 August 1984, the Subcommission on Prevention of Discrimination and Protection of Minorities adopted resolution 1984/20 in which it decided to appoint a Special Rapporteur, Leandro Despouy, to conduct a comprehensive study on the relationship between human rights and disability. His report, *Human Rights and Disabled Persons*, was published in 1993 (E.92.XIV.4). Mr. Despouy made it clear that disability is a human rights concern, in which the United Nations monitoring bodies should be involved. Among his recommendations the following might be mentioned:

(a) After the Decade has ended, the question of human rights and disability should be kept on the agendas of the General Assembly, the Economic and Social Council, the Commission on Human Rights and the Subcommission as an item of constant concern and ongoing attention;

(b) The United Nations Committee on Economic, Social and Cultural Rights should assume the supervisory task in the disability field. The Committee should receive a special mandate for this purpose.

66. In 1994, the Committee on Economic, Social and Cultural Rights assumed this responsibility by issuing a General Comment No. 5, in which the Committee made an interesting analysis of disability as a human rights issue.

67. The General Comment stated:

> The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. In addition, insofar as special treatment is necessary, States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability. Moreover, the requirement contained in article 2 of the Covenant that the rights 'enunciated ... will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability.

68. At its fifty-fourth session in 1998, the Commission on Human Rights decided to discuss issues relating to human rights of persons with disabilities. I had the opportunity to speak on the item. In my statement I made a series of

recommendations, which to a large extent were taken into account by the Commission. A number of Member States and NGOs also contributed to the discussion.

69. As a result of the deliberations, the Commission adopted resolution 1998/31, in which the Commission made a series of statements and recommendations of great importance for future developments in this area.

70. In the first paragraph of the resolution, the Commission recognized the Standard Rules as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning disabled people. It encouraged NGOs in the disability field to provide relevant information to the Committee on Economic, Social and Cultural Rights and to the Office of the United Nations High Commissioner for Human Rights and to avail themselves of the technical assistance of the Office of the High Commissioner to assist them to function effectively in the human rights sphere. In the resolution, the Commission also encouraged all the treaty bodies to monitor the compliance of States with their commitments in order to ensure full enjoyment of rights by persons with disabilities and called upon Governments to cover fully the question of human rights of persons with disabilities, when reporting under the relevant United Nations human rights instruments. The Commission invited the Special Rapporteur of the Commission for Social Development to address the Commission on Human Rights at its fifty-sixth session, which will take place in 2000. Finally, the Commission requested the Secretary-General to report biennially to the General Assembly on the progress of efforts to ensure the full recognition and enjoyment of human rights of persons with disabilities.

D. Cooperation with the Secretariat and other organizations of the United Nations system

71. A special unit within the Division for Social Policy and Development of the Department of Economic and Social Affairs has the mandate, given earlier in connection with the International Year of Disabled Persons, to serve as the focal point on disability within the United Nations system. The unit is currently strengthening this role by building an Internet information base and by launching a project to create a library by compiling information on international norms and standards. It is also the task of the unit to make an appraisal and evaluation of the World Programme of Action on a quinquennial basis and to provide support to me in my monitoring task. The unit is also responsible for the United Nations Voluntary Fund on Disability which co-finances catalytic projects in developing and transition countries.

72. The involvement in disability by the Statistics Division of the Department of Economic and Social Affairs has grown during the last five years. The work now is mainly directed towards the two important areas of improving statistical concepts, methods and data collection programmes and compiling and disseminating statistical data on disability.

73. As can be seen in the report by the Secretary-General to the fifty-fourth session of the General Assembly, many United Nations funds, programmes and specialized agencies are also involved in the disability field.

74. The United Nations Development Programme (UNDP), the United Nations Children's Fund (UNICEF), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and WHO are involved in policy development in their respective fields of competence. My impression is that the Standard Rules serve as a basic policy document in this process. In the case of WHO, the new policy document, currently being drafted, explicitly builds on the Rules. In the comparison I have made of the contents of the Rules and documents such as the Salamanca Statement of 1994 and ILO Convention 159, I have found that the language sometimes differs but the goals and principles are identical.

75. All of the above organizations have a considerable number of country projects financed through a variety of governmental or inter-governmental funding mechanisms. In some cases they cooperate in country projects, but to my knowledge this does not occur regularly.

76. In my work I have cooperated with these United Nations entities in many different ways. Local representatives have often participated in the discussions during my country missions. In some cases I have made visits to the headquarters of the organizations to discuss certain issues. As I mentioned earlier, they have made presentations at the two panel meetings, held in 1997 and 1998. The Office of the United Nations High Commissioner on Human Rights also participated in the meetings.

77. During the International Decade of Disabled Persons and for a number of years subsequently, there was a special inter-agency mechanism for coordination and exchange of experience within the United Nations system. As part of reforms of the subsidiary bodies of the system's Administrative Committee on Coordination, the formal yearly meetings were typically replaced by more informal ad hoc mechanisms. A core group, consisting of ILO, UNESCO, UNICEF and WHO, has been meeting informally.

During recent years the group has grown. I have been invited to take part and have done so when possible.

78. In my former report to the Commission for Social Development I stated that no serious efforts were made by key international development cooperation agencies to integrate disability measures into their mainstream activities posing the risk that disability, once again, will be left out or marginalized in such development programmes. During the three past years, an encouraging development has begun.

79. In March 1998, I participated in a seminar on disability policy organized by the Human Development Department of the World Bank. Some 30 people from the bank staff (including the head of the Human Development Department) participated in the discussions. At the seminar we were informed that the Bank was initiating a process to develop a disability policy within the organization. Since then, many new initiatives have been taken and representatives of the World Bank have started to participate more actively in international disability affairs.

80. According to a recent report, the basic United Nations documents provide a framework for the activities of the World Bank on disability issues. To effectively implement disability interventions, the World Bank relies on partnership with other agencies, which is fostered through involvement in appropriate conferences and working groups. The Bank recognizes the economic and social value of increasing the participation of disabled citizens in society and has a growing number of projects in this area. A directory of Bank projects has been created and will be updated periodically since it is expected that the number of projects will continue to grow.

81. The World Bank has recently taken a number of initiatives to expand the incorporation of persons with disabilities in the World Bank's work and to help countries to implement their own goals related to access, inclusion, and poverty reduction. As part of the preparations for the next World Development Report, which will focus on poverty, the Bank is preparing an analysis of the linkages between disability and poverty in the developing world.

82. In order to increase the quality of World Bank support to disabled people in developing countries, the Bank is collecting information on good practice in development assistance. Other measures taken to expand the incorporation of persons with disabilities in the Bank's work include the development of an internal working group around the theme of disability.

83. Finally, it should be added that both the Asian Development Bank and the Inter-American Development Bank have recently initiated measures to improve their handling of disability matters.

Informal consultative meeting

84. As a joint initiative by WHO and UNDP, an informal consultative meeting was organized in June 1999. The overall objective of the meeting was to discuss the development of a more effective, collaborative approach to disability that will integrate the broad areas of disability prevention, rehabilitation and human rights issues. Representatives of United Nations agencies, including the World Bank as well as a selected number of NGOs active in the field of disability, participated. I accepted an invitation to chair the meeting.

85. After discussions concerning the global situation, present activities in relation to disability, rights, needs and opportunities for global action and current barriers and means and structure for future collaboration, the meeting agreed on the following appraisal of the situation:

(a) Extensive progress was made during the 1990s, both politically and operationally, but disability has not yet obtained a prominent place on the international development agenda. This is surprising given the large and growing number of people with disabilities;

(b) There is a need for improved data on disability. Better methodologies, new tools for data collection and analysis should be developed and applied;

(c) There is also a need for each United Nations organization to make disability a higher priority;

(d) Although the United Nations and its NGO partners have supported useful activities, including joint activities between various organizations, their efforts remain fragmented at country level and lack follow-up mechanisms;

(e) Need and interest was expressed in developing a common inter-agency agenda in support of "disability-friendly" policies and programmes at national level, with defined components and inputs from each organization;

(f) Recognition and interest was expressed in working through the resident United Nations coordinator system at country level;

(g) Participants expressed an interest in facilitating inter-agency collaboration at global level, through an appropriate mechanism, without adding an additional administrative layer and impairing the mandate of each organization concerned;

(h) The possibility of creating a subcommittee on disability within the Administrative Committee on

Coordination should be explored. It could serve as the inter-agency forum, which would ensure a more prominent and visible place for disability.

E. Cooperation with international non-governmental organizations

86. One of the most characteristic features of this United Nations monitoring exercise is the close cooperation with the major international NGOs in the disability field. During the drafting of the Standard Rules in the beginning of the 1990s, these international NGOs were already directly involved. I described their active participation in my report to this Commission in 1997.

87. The six organizations that responded to the invitation from the United Nations and formed the panel of experts in 1994 have played a special role within the project. It should, however, be mentioned that a number of other organizations have also actively supported and used the Rules in their work.

88. The six organizations have a network of more than 600 national affiliates. These national organizations have had an important role during my visits to countries. I have often communicated with them in preparing my visits. They have participated in discussions with governments and I have tried to involve them in the follow-up action resulting from my visits.

89. In recent reports to my office, the six organizations have informed me that they continue to use the Standard Rules actively in their work. The user guides and other educational material in connection with the Rules, which were developed during the first monitoring period, are still in use. During this second period, new conferences and seminars for organization officers and members have been organized. There are examples of organizations that have appointed special officers to coordinate the work with the Rules. Some of the organizations report that they use certain aspects of the Rules in their efforts to improve services or access.

90. The organizations also report that translation of the Rules into more national languages continues. The World Blind Union is serving its member organizations with Braille versions of the Rules in a number of languages and Inclusion International reports that the Rules are available in easy-to-read versions in several languages.

91. Finally it should be mentioned that, during the period from 1997 to 1999, the International Disability Foundation ran an advocacy and action programme on the implementation of the Standard Rules. This programme was conceived by the Foundation to create opportunities for national disability organizations to work for the implementation of the Rules. The programme has made financial and technical resources available for disability organizations in six African countries. The responsibility for each country programme is in the hands of a steering committee, composed of representatives of national disability organizations. Funds for this programme have come from the Danish International Development Agency (DANIDA) and the International Disability Foundation.

F. Promoting special dimensions

1. Children with disabilities

92. On 6 October 1997, the Committee on the Rights of the Child held a General Discussion Day in Geneva. In an outline prepared for the event, the Committee stressed that throughout history children with disabilities had been, and in many societies still were, denied access to education, family life, adequate health care, opportunities for play or for training and the right to participate in normal child activities. In spite of the fact that these children were experiencing a form of social exclusion representing a denial of their basic rights as enshrined in the Convention, their plight rarely figured high on the national or international agenda and they tended to remain invisible.

93. A number of Committee members and representatives of United Nations agencies, including the World Bank and a number of international NGOs, participated. I was invited to make a presentation from my perspective as Special Rapporteur in the field of disability policy. In my statement I made a comparison between the Convention on the Rights of the Child and the Standard Rules. I pointed to the different legal status of the two documents. I emphasized both differences and the complementarity of them. The Convention is an important statement of principles protecting the rights of all children, including children with disabilities. The Standard Rules is a whole document on disability policy, containing a much higher degree of specification and giving more guidance on what should be done and how it should be done. Measures to combat exclusion and bad conditions must be taken in two main areas — support to the individual and measures to create accessibility. I further pointed out that the Convention is rather vague in its support for the accessibility dimension.

94. Finally, I made the following suggestions for more developed cooperation between myself, as Special Rapporteur, and the Committee:

(a) Discussion of further action concerning children with disabilities on the basis of an analysis of reports from Member States on the implementation of the Convention;

(b) Further surveys on the implementation of the Standard Rules should be operated in consultation with the Committee on the Rights of the Child;

(c) Cooperation to eliminate discrimination of children with disabilities in mainstream education programmes;

(d) Cooperation to develop information about good practice;

(e) Consideration of the possibility of involving the panel of experts, established as part of the monitoring mechanism in connection with the Standard Rules.

95. At its 419th meeting, the Committee on the Rights of the Child adopted a number of key issues and recommendations, and, *inter alia*, brought up the issue of establishing a working group to prepare a plan of action.

96. Acting on the recommendation to consider a working group, Disability Awareness in Action (a collaborative project between a number of disability organizations) took the initiative of establishing a working group to consider further the many issues brought up during the general discussion day. The working group consists of international organizations of disabled people (World Blind Union, World Federation of the Deaf, Inclusion International and Disabled Peoples' International), organizations working for the rights of the child (International Save the Children Alliance, Child Rights Centre) and one member of the Committee on the Rights of the Child. I have agreed to chair the working group.

97. The group has held two meetings during 1999. Among the various activities discussed in the working group, the following might be mentioned:

(a) Generally, the main purpose of the working group is to provide more information and better tools for monitoring the situation of disabled children within the work of the Committee on the Rights of the Child;

(b) The group considers the possibility of organizing four regional seminars to collect more information about the situation and to give more visibility in those regions to children with disabilities;

(c) A letter to United Nations agencies to find out about their planned policies concerning children with disabilities;

(d) A discussion has started within the working group concerning the possibility of drafting a general comment to be considered by the Committee on the Rights of the Child;

(e) The issue of collecting examples of good practice has been raised and the group will find ways of promoting this.

2. Gender aspects

98. The Beijing Platform for Action includes a number of suggestions and references concerning women and girls with disabilities. In the follow-up work in connection with this document, carried out by the Commission on the Status of Women, representatives of women in the international disability NGOs have participated each year since 1996. As a result, all reports from the Commission thus far have included references to women with disabilities.

99. In 1997 a leadership seminar on gender issues was organized in Sweden with participants from many developing countries. One main objective was awareness-raising and learning to identify discrimination.

100. In my statement I analysed the Standard Rules from a gender perspective as outlined below.

101. The general presentation in the Rules is done with the understanding that the suggested guidelines and policies concern all people with disabilities, irrespective of race, gender or age. This interpretation follows the tradition used in the field of human rights.

102. There are a few direct references to the gender dimension. The most general one is the sentence, in paragraph 15 of the introduction: "The purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others".

103. The gender perspective is mentioned in some other instances in the introduction and the preamble. In Rule 4 on support services, Rule 6 on education and Rule 9 on family life and personal integrity special attention is drawn to the needs of girls and women with disabilities.

104. The Standard Rules must always be related to the concrete situation in each country. In so doing, there is a need for interpretation and for placing emphasis or focus on certain conditions or circumstances. It is, for instance, often necessary to emphasize the need to include special measures for disabled women in adult education, medical care, rehabilitation and the provision of technical aids.

105. It is very important to combine the provisions of the Standard Rules and those contained in the Convention on the Elimination of All Forms of Discrimination against Women. This possibility must be further developed through cooperation between the appropriate bodies within the United Nations, the specialized agencies, international NGOs and all concerned entities at the national level.

106. Finally, in reply to the question on the gender dimension, of course, one would have wished for a more clearly spelt out gender dimension in the Standard Rules. However, by using all the different means that I have pointed out, I am sure that we can also make it a strong and useful tool in the struggle for empowerment and full participation by disabled women in their societies.

3. Persons with developmental and psychiatric disabilities

107. In its resolution 35/2, the Commission for Social Development emphasized the need to study the dimension of human rights for persons with developmental and psychiatric disabilities. The reason for particularly focussing on the situation of these groups is, of course, that they are among the most neglected and marginalized in society. There are many similarities in the situation for persons with developmental and psychiatric disabilities. Both groups have often been hidden away, either in families or in institutions, and affected by negative attitudes and prejudice.

108. In my second global survey on the implementation of the Standard Rules, there was a section on the protection of the human rights of disabled people. One general conclusion drawn from this investigation is that there are serious problems in the human rights area, for instance in important fields such as the right to vote and stand for election, the right to appear before a court of law and the right to marriage and to property. Obviously the people most affected were those with developmental and psychiatric disabilities.

109. However, in the work for the rights of these two groups there are also differences. In the field of developmental disabilities, there is a strong and well developed world organization — Inclusion International. This organization effectively advocates for the rights of persons with developmental disabilities and conducts many different projects around the world to improve the situation both in developing countries and in countries in transition. There are programmes to mobilize families in so-called parent action groups. Community-based rehabilitation is used to develop family support in order for families to be able to keep children with developmental disabilities at home. The issue of improving the situation of people with developmental disabilities living in large institutions is an issue in many different countries. One way to handle this is to develop family support as an alternative to admission to such institutions. Another way is to improve the living conditions, materially and socially, for the people living in those institutions.

110. During this second period of monitoring I have participated in discussions concerning the situation of persons with developmental disabilities in several ways. I have been invited to attend conferences held by Inclusion International and have worked with its representatives in a number of countries, often in seminars with Governments and national organizations.

111. It has been much more difficult to find forums for the discussion of matters concerning persons with psychiatric disabilities. After the Panel meeting in May 1998, I discussed with representatives of Psychiatric Users how to bring the rights of people with psychiatric disabilities more into focus in my work. We identified two major opportunities, which were both scheduled for September 1999. One was a conference in Chennai, India, which was one of the first international initiatives where the situation of people with disabilities from mental illness was discussed in the light of the Standard Rules. The other event was the Congress of the World Federation for Mental Health where it was possible to get a number of users together to discuss how to develop a world organization of psychiatric users.

112. In my statement at the Chennai conference I commented on what the international community had to offer in the form of guidelines for improving the living conditions of persons with psychiatric disabilities. The Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care, contained in the annex to General Assembly resolution 46/119 of 17 December 1991, provides clear guidelines concerning the protection of fundamental rights and freedoms of persons with mental illness. It also provides concrete guidelines for the establishment of mental health facilities and care, although some users do not agree on the recommendations concerning involuntary treatment and detention.

113. In the area of measures for the active participation of people with psychiatric disabilities in the societies they belong to, the document does not give any concrete guidance. In our work for this group it therefore seems necessary to use both these principles and the Standard Rules as a basis.

114. In the Standard Rules all recommendations and guidelines are valid for all groups of disabled people. The concept of disability, which is applied in the Rules, makes

this quite clear. Let me quote the following from paragraph 17 of the introduction: "The term 'disability' summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature".

115. It is obvious that the recommendations and guidelines of the Standard Rules are more concrete concerning other groups than mentally disabled people. Actually, there are few direct references to people with mental disabilities in the Rules.

116. At the Congress of the World Federation for Mental Health held in Chile in September 1999, a number of users gathered to prepare a plan of action for the establishment of a world organization with stronger representation than today. According to this plan, preparations have been made to mobilize users and survivors all over the world. The intention is to hold the founding meeting of this new world organization in December 2001.

III. Observations and conclusions

A. The Standard Rules document

117. It is obvious that more progress in policy development and legislation has taken place in the 1990s than in earlier decades. It is also evident that the progress during the last 10 years is clearly connected with the International Year of Disabled Persons (1981), the World Programme of Action (1982) and the political process initiated at that time. A considerable number of countries throughout the world have adopted new legislation and developed national policies in harmony with international guidelines. In this process, the Standard Rules have played a significant role. Above all the Standard Rules have clearly defined the role of the State in implementing measures towards full participation and equal opportunities, strengthened the human rights dimensions and provided an active monitoring mechanism within the United Nations system.

118. The Standard Rules document has many merits. It is concise and provides a concentrated presentation of guidelines in a number of areas. These guidelines have been used in a great number of countries in many different ways. The fact that the recommendations are at the international level has created room for national application and adjustment to regional and local circumstances.

119. There are, however, shortcomings in the Standard Rules document. Some dimensions of disability policy have not been treated sufficiently. This is true concerning children with disabilities, in the gender dimension and for certain groups, mainly persons with developmental and psychiatric disabilities. It has been pointed out that the Rules do not include a strategy for improving living conditions of disabled people in regions with extreme poverty. Disabled persons in refugee or emergency situations are other areas that have not been dealt with. As I pointed out in my previous report to the Commission for Social Development (A/52/56) the whole area of housing has not been included. Among other things this means that there is no guidance concerning the handling of the institutions where a great number of persons with disabilities still spend their whole lives under miserable circumstances. The important events in the human rights area during the 1990s should perhaps also be more clearly reflected. (See paras. 157-160 below)

120. One of the most prominent features of the Standard Rules is the monitoring mechanism. The terms of reference for this function, presented in section IV of the document, are far reaching and could motivate considerable resources for implementation. In point of fact, the available resources have been limited, although it must be emphasized that the funds made available for this project through extrabudgetary means have been more generous than for most other projects in the field of social development. The way the purpose of the monitoring is set out, emphasis should be on promotion, assistance and assessment. Within available resources, I have tried to include activities in all these areas.

B. The role of the Special Rapporteur

121. In my role as Special Rapporteur I have performed several different functions. I have introduced the Standard Rules at a great number of both international and national conferences and seminars. On such occasions I have explained the background of the Rules and their relation to other United Nations documents. One important task during country visits has been to assist in interpreting the meaning of the Rules and in finding relevant applications in given situations. In some cases Governments have asked for advice concerning how to proceed in certain areas. In other cases our discussions have concerned priorities.

122. Many people I have worked with have told me that one important function of my work has been to provide a catalytical function. I have brought Governments and other concerned parties together for common discussions, I have been instrumental in getting disability onto the agenda of

Governments and I have sometimes initiated dialogues between the organizations concerned.

123. The media coverage during my visits has been of different character. In some cases my visit has raised a lot of attention while on other visits very little has been said or written.

124. It is obvious that my personal background, a disabled person with experience as a parliamentarian and Government minister, has been important, especially in my contacts with Government representatives.

125. As my visits have been short, it has always been important to indicate clearly how agreements or new ideas should be followed up. In most cases this has been taken care of by the different actors in the country. In some cases I have sent follow-up letters, summarizing what has been agreed upon and pointing out things that should be done. There are cases where these letters have become short-term tools for implementation.

126. As mentioned earlier, I have assessed the level of implementation in Member States through the distribution of questionnaires to both Governments and national NGOs. These monitoring surveys have concentrated on a number of Rules. In this way, the substance of 10 of the 22 Rules have been explored. The first survey consisted of a few general questions about how Governments had received the Standard Rules. Thirty-eight Governments replied. In the second and the third surveys, the number of Governments responding has been relatively high (83 and 104). In this way we have assembled a fairly large volume of information, which I have been able to use in my work and which is also available for follow-up by United Nations agencies and others. The fact that national NGOs have also replied to these surveys (165 in the second and 115 in the third survey) has brought an additional dimension. It is obvious that organizations and Governments often do not make the same assessment of the situation. This could form the basis for further national discussions.

C. The contribution of non-governmental organizations

127. One of the great assets of this monitoring mechanism is the close cooperation with the major international organizations in the disability field. This has been important in two different ways. The panel of experts, established by these organizations, has played an active consultative role in support of my work. The organizations behind the panel also provide an extensive international network with more than 600 national affiliates in about 160 Member States. I have the impression that this form of close cooperation between the United Nations and international NGOs is unique and could serve as a model for other areas. Above all it is important to ensure that this form of cooperation will continue as part of a future monitoring mechanism.

128. The panel organizations have issued information material and user guidelines to national members to facilitate the use of the Rules. Several workshops and training seminars have been organized regionally, often co-funded by the United Nations Voluntary Fund on Disability. The Standard Rules and their implementation have continued to be an item on the agenda of the international congresses of the panel organizations.

129. During my visits to various countries, I have held separate meetings with the representatives of the organizations to find out how they view the situation. They have often also participated in my discussions with Governments. To keep the organizations representing the interests of persons with disabilities involved and informed has often proved to be the best guarantee for keeping disability on the national agenda and for the follow-up of agreements and new ideas.

D. Response by Member States

130. How have Member States responded to the Standard Rules and to our monitoring efforts? My general impression is that the Rules are well known by disability experts in most Government administrations around the world and that they are being widely used in a large number of countries. They are being used to create new legislation, as a basis for plans of action and sometimes as an evaluation tool to assess the situation. Conferences and training seminars have been organized to introduce the contents of the Rules or to discuss their application in certain areas.

131. In my discussions with Governments a great number of different subjects have been raised. On occasion, Governments may have been planning to formulate a new disability policy, but more often they have been looking for a strategy to implement a new policy or legislation. Often Governments have wanted to know how other countries have used the Standard Rules or how they have solved a certain problem. One issue, which tends to come up frequently, concerns the distribution of responsibility. Oftentimes, when Governments adopt the principle of inclusion or mainstreaming, the ministries responsible for the implementation of the policy run into conflicts with other ministries and public institutions, that are reluctant to accept

disability concerns as their responsibility. The notion that disability is a concern solely for disability specialists is deeply rooted worldwide. Other important issues that have formed the basis for dialogue are: cooperation and coordination issues; moving from an old system into the application of modern principles; how to change negative attitudes towards disability among the general population; de-institutionalization; and issues in areas such as accessibility and education.

132. The response of Member States to our monitoring could also be expressed in terms of providing information to our global surveys. More than 100 Governments have provided information on a number of aspects of implementation. The extensive information received can be used for various follow-up actions. One such area is the serious human rights problems revealed by the second global survey. This accumulated information has also made it possible to describe certain global phenomena, such as the establishment of structures for cooperation between Governments and national NGOs, common serious problems in lack of access to education and the fact that disability measures are seldom included in general programmes of development cooperation. All those Governments that have responded to our extensive questionnaires have made considerable efforts in providing information on a number of areas. Naturally this also has had an awareness-raising effect in government administrations. Unfortunately, there are a number of countries, in most cases small and poor countries, from which we have no information. I have not been invited to visit them and they have not responded to any of our surveys. Probably the main reason for not participating in our monitoring exercise is a lack of resources or knowledge about disability matters. The fact that the Special Rapporteur only visits countries upon request has naturally also been a limiting factor in this context.

E. Outcome of the third survey

133. The results presented in this survey must be viewed from the fact that 77 of the 104 responding Member States, by a classification according to socio-economic criteria, are developing countries. From this perspective a strikingly high proportion of Governments indicated the existence of medical services (99 countries of 104 responding), rehabilitation (73 of 102) and the provision of devices and equipment (87 of 96) to persons with disabilities. This is an encouraging result.

134. The fact that services exist in a country and that there is government involvement signifies that this kind of programme has been established, that the national competence in the field can grow and that thereby a foundation has been laid for further development. However, it should be emphasized that, affirmative replies notwithstanding, very different situations may exist. Countries with full coverage of existing needs and countries where a national centre has been established, covering perhaps 1 or 2 percent of the actual need, may both indicate that a national programme exists.

135. The full report prepared by WHO will hopefully make a more profound analysis possible, especially as WHO will be in a position to take replies from both governments and national NGOs into account.

136. A follow-up study on the availability of services in a selected number of countries could increase our understanding of the situation.

137. It is interesting to observe that community-based rehabilitation and other forms of decentralized services exist in so many countries.

138. Concerning the provision of devices and equipment for disabled people, it is encouraging to note that a majority of countries supply services to a large number of defined groups.

139. Persons with disabilities, their families and their organizations are obviously involved in various aspects of providing services in a number of countries, even if the indicated frequencies are considerably lower than for the existence of services.

140. Finally, since the right to influence and involvement by persons with disabilities and their organizations is a matter of priority in the Standard Rules, measures to strengthen and ensure this influence should be taken by more Governments.

F. Legislation

141. Both the adoption of the Standard Rules and developments in the human rights area has increased the pressure for modernized legislation. A considerable number of countries have developed their legislation concerning persons with disabilities. Some have included disability in an anti-discrimination clause in their constitutions. This has, in most cases, been done in connection with a major revision of the constitution. In the vast majority of cases, countries have chosen to establish special laws on disability and not to integrate disability concerns into general legislation. There are great variations both in form and subjects covered

under these new laws. There are also great variations in the area of enforcement mechanisms. One common challenge is to define the group or groups of people entitled to enjoy the various provisions of the law. As far as I know, the first initiative to analyse the legal developments that have taken place during the 1990s on a global basis was the United Nations Consultative Expert Group Meeting on International Norms and Standards Relating to Disability held at Berkeley from December 8 to 12 1998. The report of the meeting included a number of valuable recommendations and suggestions both in relation to the development of national legislation and concerning international cooperation. The initiative to compile national legislation to create a library on international norms and standards taken by the Disability Programme within the Secretariat is highly commendable.

G. Human rights development

142. As discussed in paragraphs 63 to 70 above, significant progress has recently taken place in the area of human rights and disability. The essence of this development is the recognition that disability and disability-related problems is a concern for the United Nations human rights monitoring system. This is probably the most important progress for the cause of disabled persons in recent years. To use this opportunity maximally, the challenge now is to develop awareness and competence for this new task within the United Nations monitoring system, in Government administration and among NGOs. As far as I know, little has happened in this area since the adoption of resolution 1998/31 by the Commission on Human Rights. Therefore, urgent need for follow-up action in this field still exists.

H. Children with disabilities

143. Some positive developments have taken place during this second monitoring period. The discussion day held in October 1997, organized by the Committee on the Rights of the Child, resulted in increased awareness of the many dimensions of this issue and stimulated the Committee to adopt a number of recommendations for further action. The working group established by NGOs in the fields of disability and children's rights in 1999 to follow up on some of these recommendations has the potential to provide valuable information and knowledge in this field.

144. Many United Nations agencies, in particular UNICEF, UNESCO, WHO and ILO, have programmes concerning children with disabilities. It is important that these efforts are well coordinated and that the acting agencies make sure that a holistic approach can be maintained and that no important aspect is left out.

145. I notice that there is a growing involvement in the situation of disabled children on the part of the NGOs working in the disability field. It is necessary, however, that this involvement continue to expand. The newly created working group may contribute to such growth.

I. Gender aspects

146. It is important that the disability-related gender issues, as far as possible, are dealt with as a natural part of gender analysis in different areas. It is encouraging that, since 1997, the Commission on the Status of Women has included disability aspects in its work in different areas.

147. However, more needs to be done to improve the living conditions of girls and women with disabilities. To a large extent, the task is now to increase awareness and knowledge about the specific problems and discrimination faced by girls and women with disabilities. Information about these problems and the ability to handle them must be built in both in gender and disability programmes.

148. Some United Nations agencies have started work in this field and have the potential to play an important role in the promotion of these issues globally. International disability organizations and their national affiliates have a crucial role to play both in awareness-raising among their own members and in building up international support for the struggle for improved conditions for women and girls with disabilities. More needs to be done in these areas.

J. Persons with developmental and psychiatric disabilities

149. Both these groups are among the most marginalized in our societies. In most communities they and their families meet negative attitudes and prejudice. Their existence must be recognized in all countries and their needs made known and visible. Inclusion International is making an important contribution to mobilize parents and professionals of people with developmental disabilities in the struggle for better conditions. These efforts must be supported so that they can be continued and strengthened.

150. In the case of persons with psychiatric disabilities, there is no worldwide organization which represents their interests alone. One of the most urgent needs is to support

the attempts made by small groups of psychiatric users to organize and create a voice of their own in more countries. The plan to develop the World Federation of Psychiatric Survivors and Users into a strong and representative world organization must get support and recognition.

151. For both groups the issue of how to handle the large institutions in many countries is crucial. It involves both the issue of how to improve the living conditions for those who already live in institutions and what measures should be taken to avoid institutionalization of individuals in the future. It is therefore equally necessary to develop support services and programmes for both groups to make it possible to live in society with a developmental or a psychiatric disability. As far as I have been able to find out, the United Nations and its agencies have not adopted policy in this important area.

152. The United Nations document entitled "Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care" provides clear and progressive guidelines for the treatment and care for persons with mental illness. It would be interesting to study how far Member States have come in their implementation of these guidelines. To my knowledge, no such follow-up study has been made since the adoption of the resolution.

K. Future involvement by the United Nations

153. My mandate as Special Rapporteur ends in August 2000. Consequently, the Commission for Social Development has to consider at its thirty-eighth session if and how this monitoring exercise should continue. Important progress has been made since the adoption of the Standard Rules. Many more Governments have engaged themselves in policy development and created national structures for planning and coordination in the disability field. Disability will be a much more prominent issue in the area of human rights. A structure for cooperation between the United Nations system and international NGOs in the disability field has developed. The Standard Rules have proved to be a useful tool in the development of government policies and legislation.

154. This new development has also led to increased awareness and new challenges. How can we make use of the new situation in the field of human rights? What should be done about the shortcomings of the Standard Rules document? What action should be taken to improve the situation of persons with developmental and psychiatric disabilities? How could the present cooperation between the United Nations system and international NGOs be preserved and developed in the future?

155. When discussing the future monitoring of the Standard Rules it is necessary to take new developments into account. I have discussed these issues with the Panel of Experts and I have received a number of valuable responses to a letter concerning future options that I circulated in the beginning of 1999.

1. Strengthening the United Nations documents on disability

156. The Standard Rules are being used in a large number of countries. We also know that there are shortcomings and gaps in the document, which should be corrected. I have specified a number of such areas in paragraphs 157 to 160 of the present report. The Commission for Social Development should consider forms for complementing and developing the Rules to cover new or unaddressed areas in the disability field.

157. Ten years ago the United Nations General Assembly rejected proposals for a convention on the rights of persons with disabilities. The international movement of disabled people never fully accepted the reasons for that decision. Many find it difficult to see the difference in principle between a special convention in this area as compared to other areas where conventions already exist. Since there have been significant developments in national policies and laws worldwide during these 10 years, it is possible that a larger number of governments would now accept the elaboration of a convention. The question is, however, if the number of supportive governments would be large enough to make the development of a convention really meaningful.

158. One crucial issue in this context is what level of specification would be chosen in a convention. One idea could be to develop the Standard Rules and to build a convention on a principal basis and link it to the Rules.

159. The development in the human rights area calls for further initiatives. One option, which in my opinion should be considered by the Commission on Human Rights, is to elaborate special protocols or comments developing the different aspects of human rights concerns for persons with disabilities. The purpose of this should be to improve the standards of monitoring. At least temporarily this could be an alternative to elaborating a special convention.

2. Options for monitoring

160. The special monitoring mechanism, which was constructed for monitoring the implementation of the

Standard Rules, includes promotion of the Rules, assistance to Member States and assessment of the situation. My experience is that this is a very useful combination of tasks. It would therefore not be appropriate to reduce the monitoring to a more passive function of observing what happens. Based on my experience, I support a continuation of a monitoring mechanism with the same basic functions.

161. As far as I can understand there are two main options if monitoring is to be continued. One is to integrate the function into the Secretariat and the other is to continue in the same manner as before. The present structure, with a Panel of Experts appointed by international disability organizations, should be maintained in connection with either of these options. A third possibility, which is interesting but probably too demanding in terms of resources, would be to add to a global function of regional rapporteurs who would do most of the travelling.

162. If the monitoring is to be carried out in a meaningful and effective manner, there has to be sufficient economic resources. It would, of course, be an advantage, if funds could be allocated through regular sources. If not, extrabudgetary means must be added.

163. As I have mentioned in the section on human rights, I have been invited to share my experience with the Commission on Human Rights. In that connection it has been suggested that a function serving both the Commission on Human Rights and the Commission for Social Development should be considered. I do not know if this is technically possible or if it has occurred before. As an expression of the need to use a holistic approach and create close cooperation between different United Nations entities in the same field, I think it is interesting. Most important of all in this context is, however, that mechanisms are established so that from now on disability can be monitored both from a human rights and a social development perspective.

3. Improved coordination within the United Nations system

164. It is clearly illustrated both in the report by the Secretary-General to the fifty-fourth session of the General Assembly and in the present report that many United Nations agencies have extensive programmes in the disability field. There is a need for improved coordination both on the country level and internationally between these agencies. I raised this issue in my previous report and suggested that the formal inter-agency mechanism, which existed during the Decade of Disabled Persons (1983-1992), should be re-established on a regular footing. As more actors have entered the disability field and as more activities are being carried out, there is a strong need for better coordination of efforts, exchange of experience and sharing of information. In the absence of an initiative for a permanent solution, agencies hold informal consultations on an annual basis. At the meeting of agencies and NGOs in June 1999, it was stated that there is a need to facilitate inter-agency collaboration at global level, through an appropriate mechanism, without adding an additional administrative layer and impairing the mandate of each organization concerned. This meeting also suggested that the possibility of creating a subcommittee on disability under the Administrative Committee on Coordination, which would ensure a more prominent and visible profile for disability, should be explored.

4. Awareness-raising and campaigns

165. In the discussion of future possibilities suggestions have been made for both a second International Year and a second Decade of Disabled Persons. In this context, the possibility of using the regional commissions of the United Nations and other regional intergovernmental bodies for such initiatives has been suggested. One good example of what can be achieved in this way is the Decade of Disabled Persons (1993-2002) of the Economic and Social Commission for Asia and the Pacific. There are also proposals for regional decades in Africa and Europe. In the American region, the Organization of American States has recently adopted a Convention on the Rights of Disabled People. It is expected that this will be followed by regional implementation efforts.

166. Taking all these regional initiatives into account, I think that there is no reason to initiate any global campaigns at the present time. The role of the United Nations should rather be to support the regional initiatives in all possible ways and to make efforts to coordinate and create opportunities for the exchange of information.